

February 28, 2013

Marilyn Tavenner
Acting Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services

Submitted online at www.regulations.org

**Re: CMS_FRDOC_0001-1121
Single Streamlined Insurance Marketplace Application**

Dear Administrator Tavenner:

The Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to submit comments on the proposed single streamlined Insurance Market Application. DREDF is a leading national law and policy center that works to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. We are committed to eliminating barriers and increasing access to insurance coverage and effective healthcare for people with disabilities, and eliminating persistent health disparities that affect the length and quality of their lives.

Introduction

The single streamlined application proposed by the Centers for Medicare and Medicaid Services (CMS) has the potential to remove or ease application and eligibility barriers commonly encountered by people with disabilities, both as consumers of private health insurance and beneficiaries of public programs. However, the streamlined application's promise for many people with disabilities will only be realized if all routes of application are fully accessible, and to the extent that the application itself adequately identifies people with disabilities who may need and qualify for more extensive health care services than those available to persons who qualify for Medicaid on the basis of their Modified Adjusted Gross Income (MAGI) levels. Moreover, in addition to the need for accurate individual applicant determination, the streamlined application has the important potential to capture data that will help government and private entities to identify the impact of disability health and healthcare disparities, but only if validated data questions are included in the application.

CMS must ensure that the single, streamlined application and the application process for insurance affordability programs is fully accessible to, and usable by, all users. The paper application must be readily available in alternative formats such as large font print, Braille, and electronic disc, and people with disabilities, including those who are blind or have low vision or are Deaf or hearing impaired, must be actively notified of their right to receive alternative formats and reasonable accommodations and policy modifications in the application process. Further, persons with intellectual, cognitive, and learning disabilities may require insurance enrollment and Exchange Marketplace information to be written at an accessible reading level, preferably at the third grade

level. Any instructional online videos must be closed-captioned. Navigators responsible for providing assistance with the application process must be trained to recognize and address the needs of people with disabilities, and the training should extend throughout any community-based organizations involved with the Navigator process. As a matter of principle, decisions about the kinds of accessibility measures that will be needed and offered in the application process should be made with input from focus groups that include or are made up of people with various disabilities. Finally and significantly, the questions that collect disability data on the single, streamlined application must be enhanced and then standardized through all modes of application, and representatives should be able to provide explanations and examples of the kind of information requested through the questions.

Accessibility of Single Streamlined Application

The application is the initial entry point to health insurance and is a vital component of the Affordable Care Act's (ACA) "no wrong door" approach to enrollment. Yet, people with disabilities may suffer erroneous denials of eligibility because they cannot independently see and read a standard print application or an inaccessible online PDF application, or because they do not understand what information to provide. Indeed, they may be prevented or dissuaded from accessing the insurance marketplace altogether, undermining the goal of the ACA to expand affordable insurance coverage for all Americans.¹

The federally facilitated exchange (FFE) must comply with Title VI of the Civil Rights Act, Sections 501, 504 and 508 of the Rehabilitation Act, and Section 1557 of the ACA. To prevent discrimination against people with disabilities, the FFE must ensure reasonable accommodations and policy modification for both consumers and FFE employees. When providing effective communication, primary consideration must be given to the request of the individual with a disability.² In addition to compliance with applicable laws, a fully accessible application would benefit all entities engaged in enrollment, outreach, and education. Community-based organizations will provide invaluable assistance through their participation in Exchange and Medicaid outreach and education, but may have limited resources and understanding of their own

¹ Lack of insurance and underinsurance among people with disabilities is increasingly documented. The National Council on Disability's 2009 report on *The Current State of Health Care for People with Disabilities* found at pages 44-45 that: "Health care insurance availability, affordability, and coverage for important benefits – including medications, long-term care, durable medical equipment, mental health, rehabilitative and specialty care, and care coordination – are key issues for people with disabilities. Yet national surveys have reported that people with disabilities commonly experience difficulty navigating the insurance system . . . Further, although many people with disabilities have some type of health insurance, a significant number of individuals with chronic health conditions remain uninsured. According to the NHIS, nearly half of all uninsured, nonelderly adults report having a chronic condition, and almost half of those forgo medical care or prescription drugs because of the cost. Nonelderly adults who lack health insurance include people with hypertension (14 percent uninsured), high cholesterol (11 percent uninsured), heart disease (13 percent uninsured), asthma (18 percent uninsured), diabetes (15 percent uninsured), and arthritis-related conditions (12 percent uninsured.) Finally, "many working-age individuals with disabilities do not qualify for [private group plan health insurance] coverage, because they are not employed; work part time (only 31 percent of workers with part-time jobs qualify for employer group plans, compared with 82 percent of full-time workers); or their employers do not offer health insurance.

² See for example 45 C.F.R. § 85.51(a)(1)(i).

obligations under state and federal disability rights laws. The existence of readily available accessible applications in both online and alternative formats will help facilitate effective communication, and will create a baseline for standardizing ACA-related enrollment terminology for use by all entities involved in outreach, education, and training. Accessible applications can also help train navigators and enrollment agents in the new Marketplaces who will inevitably encounter consumers with disabilities, thus further aiding effective enrollment and information dissemination.

Making applications accessible at the federal level is also cost-effective for CMS and the states. For example, if the nineteen states operating state-based exchanges use the single, streamlined application but are required to make their own accessibility accommodations, the costs multiply nineteen times. A front-end federal investment results in significant efficiencies and economies of scale, benefitting virtually all Medicare and Medicaid providers who must comply with the Rehabilitation Act and Section 1557 of the ACA.

Additional Accessibility Issues

The online application must comply with Section 508 of the Rehabilitation Act and Section 1557 of ACA and be fully accessible according to Section 508 standards. The videos that CMS posted to Facebook to help explain the interactive online application process as part of the request for these comments were not close-captioned and were not in compliance with anti-discrimination laws. All videos distributed by CMS or funded with federal funds should be close-captioned to comply with Section 1557 of ACA, and Sections 508 of the Rehabilitation Act. The application must be fillable online, with sufficient time provided for those with mobility limitations or spasticity who are using adoptive equipment to fill in answers. Any security mechanisms used to gain access to a secure account, where the application can be stored or retained partially filled for later completion, cannot depend only on a high functioning visual and/or audio capacity (e.g., for example, common “Captcha” technology requires users to visually interpret distorted images or discern distorted aural messages).

Navigator Training

CMS cannot rely upon Navigators and telephone assistance centers as the sole or primary reasonable accommodation that will enable people with disabilities who want to use the Marketplaces’ application process. First and foremost, PWD have the desire and capacity to do things independently, and this is especially true when the process likely involves the submission of such confidential information as one’s social security number and other personally identifying information. If the online and paper application and application process are made fully accessible according to Section 1557 of ACA and the Rehabilitation Act, people with disabilities will experience significantly equal access. Some individuals with disabilities will require personal agency assistance, and in that event navigators must be trained to discern and meet the needs of people with disabilities so that they can be of assistance in a culturally competent manner. Telephone representatives must also be trained in the civil rights of people with disabilities to reasonable accommodations and policy modifications, and in how to provide services in a culturally competent manner, including how to use telephone or

video relay services to communicate with people who are Deaf or who have hearing impairments.

Inclusion of People with Disabilities in the Process

In the document accompanying the request for comments,³ CMS states “[w]e intend to undertake further consultation, conduct additional consumer focus groups, and engage experts in simplifying language and promoting a positive user experience based on the responses to this 30 day notice and continued stakeholder engagement.” CMS must remember that people with disabilities are stakeholders. Even more critically, people with specific disabilities will offer insights into which aspects of the application and application process that are barriers, that function well, and that need additional work, and these insights cannot be readily duplicated or foreseen by any survey or technical expert without those disabilities. Speaking personally as a long-time disability advocate, I have *never* failed to learn something about accessibility barriers that I had not previously known in my direct interactions with people with disabilities. For online architectural issues, in particular, false assumptions about what will or will not comprise a barrier will result in structural decisions that will cost *far* more to fix the more the application process is finalized. We urge CMS to immediately sponsor focus groups of people with various disabilities, and testing of the draft application by people with disabilities, to ensure that CMS has consumer input from *all* potential consumers. Various national and state disability organizations will gladly help CMS find participants with disabilities for its focus groups upon request, given sufficient and reasonable lead time.

Disability Questions on the Application

The Non-FA Paper Application contains no disability data collection questions, though racial and ethnic questions, albeit only from the primary household contact, are included. DREDF strongly recommends that racial and ethnic data must be collected for all applicants included on the form, and that enhanced disability data must also be collected for all applicants, thereby fulfilling some of the basic data collection provisions in Section 4302 of the ACA.

The proposed FA Paper Application (and online version) poses the question “Have a disability? __ yes __ no.” It then provides an alternative or additional question to this question as follows: “Needs help with activities of daily living through personal assistance services, a nursing home, or other medical facility?” __ yes __ no.” This second question seems to create a new definition of disability not found in any other federal disability law, regulation, or policy. The questions taken together assume that applicants will freely identify as “someone with a disability,” that applicants who would qualify as someone with a disability inevitably use personal assistance services, or at the very least that applicants are familiar with the phrases “activities of daily living,” and “personal assistance services” which are really terms of art. “Personal assistance

³ See CMS document “Supporting Statement for Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Affordable Insurance Exchanges, Medicaid and Children’s Health Insurance Program Agencies.”

services' is also placed in a medicalized context of nursing homes and medical facilities in the second question, which will also confuse applicants with disabilities who do need or receive chore and non-medical or quasi-medical personal assistance from family members and friends who are paid or unpaid, but may not check "yes" given how the question is written.

DREDF agrees with the comments submitted by the Consortium for Citizens with Disabilities (CCD) that there are two important purposes motivating the inclusion of disability-specific questions in all versions of the single, streamlined application. First, the questions should identify individuals who may meet disability-based eligibility criteria and therefore may both need and be eligible for the fuller services of "traditional" Medicaid, rather than expansion-based Medicaid. Second, the questions should identify individuals who are medically frail and, if eligible for Medicaid, would be exempt from the requirement to enroll in an Alternate Benefit Plan (ABP). We would add a third important purpose, which is to capture basic information about the impairment and needs of people with disabilities, and whether, where, and how they seek health insurance coverage, regardless of whether they "self-identify" as a person with a disability. All of these purposes work to the benefit of applicants with disabilities, both individually and collectively, and it is important to provide some context to applicants so they will understand that identifying as having a disability or impairment may result in receiving more tailored services at less personal cost.

We also feel strongly that the general population is not trained or adept at understanding when they may have a disability or impairment that may qualify them for Medicaid or an exemption from ABPs. Furthermore, the burden of having such an understanding and making a disability determination should not fall upon the individual. Research has consistently shown that asking people if they have a disability does not accurately identify people with disabilities. Some individuals who have chronic or serious medical conditions that would likely qualify them for Supplemental Security Income (SSI) or state disability criteria, thus making them eligible for Medicaid on the basis of disability, simply do not self-identify as "having a disability." As such, DREDF recommends first using a broadly inclusive series of screening questions in the single streamlined application, with trained state employees subsequently making a later determination on whether someone does or does not have a disability for the purpose of various state benefits. The application should simply flag those individual or family applicants who *may* qualify for Medicaid and therefore should be directed toward a further state benefit determination, certainly before obtaining private insurance through the Exchange, and even if the applicant also qualifies and initially obtains Medicaid under his or her MAGI levels.

The disability screening questions in the single streamlined application should also flag individuals who may be medically frail, even if additional information is later needed to qualify for an exemption to ABP. The current questions' emphasis on activities of daily living and personal assistance services may be more successful at capturing medically frail individuals, but the root identification and vocabulary problems still apply even here. Since the benchmark benefits available to newly eligible adults will likely be less robust than those in traditional Medicaid, applicants must have the fullest opportunity possible

a full opportunity to determine eligibility for the health insurance program that best suits their needs.

DREDF therefor strongly recommends that the application should focus on functional limitations rather than asking an individual to indicate that they have a “disability.” People will often resist the label of “disability,” but recognize that they have reduced functional capacity. This is particularly so for those who have newly acquired or worsening disabilities as a result of, for example, aging. It is common to hear an older individual deny that they are disabled, but readily acknowledge that they have trouble hearing or seeing. Without a clear explanation of the purpose for the questions, people who are applying on their own and their family members’ behalf may also be understandably fearful that affirming that an applicant “has a disability” will result in being turned down for insurance or being required to pay higher premiums or co-pays. Despite the efforts of the current administration and many other entities and organizations, the general public remains unaware of many of the ACA’s provisions and finest reforms, and the days of being unable to obtain insurance because of having a known or *unknown* disability are not that far distant. The current understanding of disability, unfortunately, is also not commonly known or embraced among the general public.

Disability is not simply the impact of impairment on, or its implications for, the individual, but also results from the interaction between an individual’s impairment and the social, economic, and built environment. This hard-fought understanding of disability recognizes the impact of prejudice, discrimination, inaccessible architectural surroundings, and lack of accommodations such as Sign Language interpreters and accessible medical examination and diagnostic equipment. It replaces the long-held belief that disability, in and of itself, equates inevitably with biologic dysfunction, disease and poor health.

In its International Classification of Functioning, Disability and Health (ICF), the World Health Organization (WHO) recognizes that factors outside the individual contribute to the experience of disability. The ICF calls disability an “umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors” including environmental and personal attributes. The ICF aims to shift the disability paradigm to universality, encompassing everyone:

Heretofore, disability has been construed as an all or none phenomenon: a distinct category to which an individual either belonged or not. The ICF, on the other hand, presents disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives. Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition...⁴

⁴ T. B. Ustun, N. K. Kostansjek, and J. Bickenback. “WHO’s ICF and Functional Status Information in Health Records.” *Health Care Financing Review* 24, no. 3 (2003): 82.

The ACA acknowledges both the prevalence of health disparities among people with disabilities and that health disparities are not the inevitable outcome of disability or disease, but are the result of complex factors including lack of disability awareness on the part of health care providers, and architectural and programmatic barriers to care. Thus, the ACA, in section 4302, calls for identifying disability status through population surveys and among applicants, recipients, or participants in federally conducted or supported health care or public health programs

The single streamlined application should incorporate appropriate screening for persons with disabilities consistent with the current understanding of disability embraced under the ACA and by the disability community, and with advances already made in the development of federal survey questions to identify persons with disabilities. This broader screening is essential to ensure that individuals begin to have access to the sufficient care for their needs.

For many years, the federal health-focused surveys have included questions that allow the identification of disability using a set of questions based either on activity limitation or functional limitation.⁵ This provides a base upon which to identify individuals with disabilities through survey questions, which can be incorporated into the single streamlined application.

Therefore, we recommend that the single streamlined application at a minimum include the six questions used by the American Community Survey (ACS) and several other federal surveys asking about functional limitations to help identify persons with disabilities. The questions should be accompanied by an explanation informing applicants that they may be entitled to a greater array of benefits if found eligible for traditional Medicaid. The questions may also help distinguish medically frail individuals who then exempt from benchmark coverage. The “ACS 6” questions have been vetted, tested, and approved for their capacity to accurately identify individuals with disabilities, and are used for data collection purposes in all federally funded health care, public health, and population data collection surveys.⁶ Should CMS eventually choose to use questions other than the ACS questions, or to introduce additional questions specifically designed to capture sub-populations of people with disabilities that may be under-included through the ACS 6y, those substitute or additional questions must be similarly vetted and tested. Until that happens, but until that happens, the inclusion of the ACS 6 will allow the single streamlined application to comply with the standards established under Section 4302 of the ACA.

⁵ A number of national population surveys conducted or supported by the federal government collect data on disability status and on health services use and expenditures. The American Community Survey (ACS) and Current Population Survey (CPS) specifically ask questions that identify survey respondents who have a disability. All the surveys with an explicit health information focus use the patient as the unit of analysis and, with only one exception, ask six or more questions about functional or activity limitation to identify respondents with disabilities.

⁶ While the single streamlined application may have additional goals specific to determining individual applicant eligibility, retention, and renewal, the applications are nonetheless also being used to collect health data that may be used to study, for example, the phenomenon of “churning” between public and private insurance, populations that are not seeing effective outreach, and needed future refinements to the applications forms and processes.

Our specific recommendations are:

- Include, at a minimum, the ACS-6 questions on the single, streamlined applications.
- CMS should also include explanatory text in the application concerning the purpose for asking the disability-related questions
- These questions should be applied to every individual on the applicant
- Online applications can include a link to additional information and examples that will help individuals ascertain how to answer the questions
- Amend the disability-related questions on the application as follows:

You may be eligible for another health coverage program that will better meet your needs and save you money if you answer yes to any of the questions below.

Do you have a physical, mental, or emotional, health condition that causes limitations in activities? ☐ Yes ☐ No (if Yes, you may skip the following six questions)

- 1) Are you/is this person deaf or does he/she have serious difficulty hearing?***
- 2) Are you/is this person or does he/she have serious difficulty seeing even when wearing glasses?***
- 3) Because of a physical, mental, or emotional condition, do you/does this person have serious difficulty concentrating, remembering, or making decisions?***
- 4) Do you/does this person have serious difficulty walking or climbing stairs?***
- 5) Do you/does this person have difficulty dressing or bathing?***
- 6) Because of a physical, mental, or emotional condition, do you/does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?***

- If CMS must consider a shortened number of disability-related questions for inclusion in its single streamlined application, then it should immediately test and take steps to validate a broad form of functional limitation question similar to the following:

Do you have a physical, mental or emotional health condition that causes limitations in activities such as hearing, seeing, concentrating, remembering, walking, bathing, or doing errands alone such as shopping (please note that this is not a complete list of possible activities)?

No limitation

some limitation

a lot of limitation

Conclusion

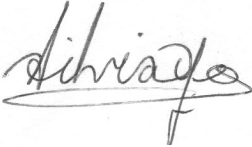
DREDF appreciates the opportunity to provide input on the single streamlined insurance

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Marketplace application and application process. We urge CMS to commit to work with the representatives and advocates from across the disability community and make the Marketplace application and the application process fully accessible and usable by people with disabilities. We urge CMS to adopt our recommendations to comply with the Rehabilitation Act and Sections 4302 and 1557 of the Affordable Care Act, and to enhance collection of disability-related data in the streamlined applications. We would be happy to answer any questions concerning the above, or to engage in further discussion concerning our recommendations.

Yours Truly,

A handwritten signature in black ink, appearing to read "Silvia Yee", with a horizontal line drawn underneath the name.

Silvia Yee
Senior Staff Attorney